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### Patients, health information, and guidelines

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## Patients, health information, and guidelines: A focus-group study

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ORIGINAL ARTICLE

## Patients, health information, and guidelines: A focus-group study

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### Abstract

**Background.** Evidence-based clinical guidelines could support shared decision-making and help patients to participate actively in their care. However, it is not well known how patients view guidelines as a source of health information. This qualitative study aimed to assess what patients know about guidelines, and what they think of their presentation formats. **Research question.** What is the role of guidelines as health information for patients and how could the implementation of evidence-based information for patients be improved? **Methods.** A qualitative study with focus groups that were built around a semi-structured topic guide. Focus groups were audiotaped and transcribed and analysed using a phenomenographic approach. **Results.** Five focus groups were carried out in 2012 with a total of 23 participants. Patients searched for health information from the Internet or consulted health professionals or their personal networks. The concepts of guidelines included instructions or standards for health professionals, information given by a health professional to the patient, and material to protect and promote the interests of patients. Some patients did not have a concept for guidelines. Patients felt that health information was abundant and its quality sometimes difficult to assess. They respected conciseness, clarity, clear structure, and specialists or well-known organizations as authors of health information. Patients would like health professionals to deliver and clarify written materials to them or point out to them the relevant Internet sites. **Conclusions.** The concept of guidelines was not well known among our interviewees; however, they expressed an interest in having more communication on health information, both written information and clarifications with their health professionals.

**Key Words:** Clinical guidelines, concepts, focus groups, Finland, general practice, patient information, patient versions

### Background

In ideal circumstances, evidence-based guidelines could help patients to participate actively in their care and improve shared decision-making. Many guidelines producers publish short versions of guidelines for patients, which are often referred to as “patient versions” [1]. However, little is known about whether patients know of or use guidelines or whether the information presented within patient versions influences patients’ healthcare decisions. A recent review did, nevertheless, find that awareness of

guidelines among the public and patients is low, that the public does not perceive guidelines more favourably than other health information, and that the purpose of patient versions is often not clear to the intended audience [2]. There have been attempts to involve patients in guideline production, and methods for this have been described [3,4].

Approaches to communicate clinical evidence to patients include written health information, numerical translation of clinical evidence, graphical representations, and decision aids [5]. A Cochrane review

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In health care, there are gaps between evidence and practice, and clinical guidelines are meant to bridge these gaps. Information from guidelines may not be easily transferred to patients.

- Patients feel that health information is abundant; they mostly search for it on the Internet and sometimes find it difficult to assess its quality.
- Patients consider guidelines to include instructions or standards for professionals, information given by health professionals to patients, and material to protect and promote the interests of patients. Some patients do not have a clear concept of what guidelines are.
- Patients would like health professionals to talk about health information and for them to deliver and clarify written materials, or point out relevant Internet sites.

on decision aids [6] indicates that decision aids are superior to usual care interventions in improving knowledge and realistic expectations of the benefits and harms of options. Research evidence also exists on different aspects of presenting information for patients [7,8]. For example, percentages are better understood than frequency formats, and absolute risks are preferred to relative risks. A plain-language summary of systematic reviews that included tabular summaries of effects and uncertainties was better understood than a more narrative summary [1], symbols can be useful [9], and tabular formats help understanding [10,11].

The gaps between evidence and practice may, in part at least, be caused by poor communication of that evidence to the people whose healthcare decisions would benefit from knowing it. An EU-funded research consortium DECIDE (<http://www.decide-collaboration.eu/>) explores methods to ensure effective communication of evidence-based recommendations targeted at key stakeholders: healthcare professionals, policy-makers, and managers, as well as patients and the general public [12]. One of the aims of the consortium is to study how presentation of the evidence could be improved to meet the information needs of the general public and patients.

The current qualitative study was planned within the DECIDE consortium. It aimed to assess the role of guidelines as a source of health information in Finland, where there has been active guidelines production since the 1990s and where the first patient versions of national guidelines were introduced in 1997. In this study we explored the concepts of guidelines among patients and their ideas on how the implementation of evidence-based information for patients could be

improved. The aim of this paper was to find out how patients currently used health information and how they comprehend the concept of guidelines. To understand the potential for improving the presentation of guideline material to patients we studied what patients thought of some selected presentation formats, and how they thought the implementation of patient versions could be improved.

## Material and methods

Focus groups provide an effective technique for exploring attitudes and needs, and factors that influence those perspectives [13]. We followed a semi-structured interview guide (Table I) in the focus groups, which were guided by two facilitators (HL and OS or JJ). The topic guide was developed in cooperation with the DECIDE study group. To study preferences with regard to presentation formats, we presented two possible graphic formats to patients (Figures 1 and 2) utilizing user-testing, which is a qualitative method embraced by the DECIDE study group [12,14].

We had a key informant (MP) outside the study group to recruit the patients who had links both to health care providers and patient organizations. She was asked to invite to the focus groups information-rich people who represent Finnish primary care patients. The groups were sampled purposefully to avoid too

Table I. Topic guide for the focus-group interviews.

### Discussion – Part 1

1. Where do you go when you need healthcare information?
2. How do you use the information? To support an immediate decision, to reinforce what they already know, to get general information about an illness/disease etc.?
3. Have you heard clinical guidelines being discussed in the news? Are you familiar with the concept of clinical guidelines?

Presentation – two types of patient information leaflets on management of bronchitis

### Discussion – Part 2

4. What are your first impressions of these potential approaches to presenting guideline information?
5. What do you like and dislike about each strategy?
6. How could these presentation formats be developed so that they would be more useful?
7. What other strategies might be available for presenting research information within guidelines?
8. Would the organization preparing the guideline influence your confidence in the guideline?

Presentation – figures and drawings

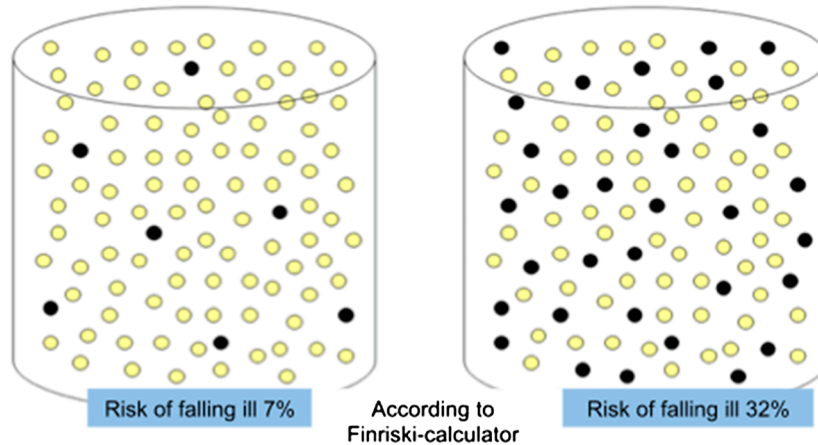
### Discussion – Part 3

9. What are your first impressions of these potential approaches to presenting guideline information?
10. What do you like and dislike about each strategy?
11. How could these presentation formats be developed so that they would be more useful?
12. Any other points you would like to raise?

## Risk of myocardial infarction or stroke in 10 years

60-year-old man, chol 5, systolic blood pressure 130, no smoking.

60-year-old man, chol 7, systolic blood pressure 180, smoking.



Both bowls present 100 people and each black ball stands for the risk of falling ill to myocardial infarction or stroke in 10 years. A person's individual risk can be compared to a lottery where one ball is picked from the bowl. Most likely a yellow ball is picked, but with bad luck it can also be a black one.

Figure 1. Drawing presenting two patients with different cardiovascular risks that was presented to the focus-group participants.

much heterogeneity within a group to enhance discussions. We continued recruiting new groups until we felt that there was saturation of the data.

The discussions were audiotaped and transcribed, and they lasted from one hour to 75 minutes. Finnish was spoken in all of them. Two authors first coded the transcripts independently (HL and OS). We applied a phenomenographic approach to study the concepts the interviewees had for health information

and guidelines [15]. We first gathered the utterances under each topic guide area and then gave an initial characterization to these. Both coders independently gathered the utterances, characterized them, and derived the main concepts of the material based on these. Finally the concepts were discussed and main findings were agreed upon. The phenomenographic approach is derived from educational research and it aims to characterize, understand, and describe the variety of human ways of understanding the world around them [16].

The DECIDE group assisted in linking the research to other patient information literature and findings in other DECIDE studies. The study was approved by the Coordinating Ethics Committee at Helsinki University Hospital on 7 February 2012 (ref: 209/13/03/00/2011). All participants gave their written informed consent.

## Results

Five focus groups were held in Finland in 2012, two in March and three in August comprising three, five, six, five, and four people, altogether 23 participants: seven men (30%) and 16 women. The demographic characteristics of the participants are presented in Table II. The first group consisted of middle-aged women in good health, the second of middle-aged patients with chronic conditions who were attending a

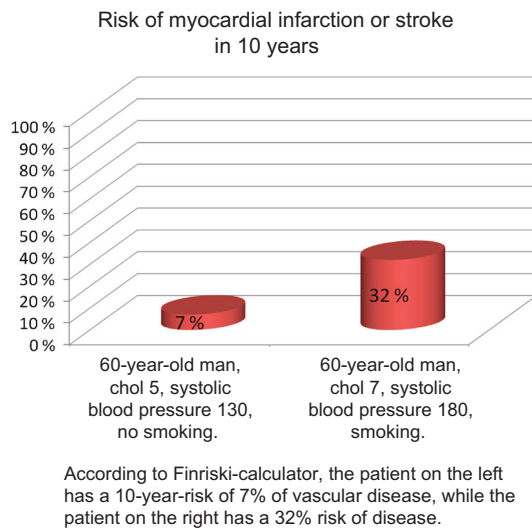


Figure 2. Bar chart presenting two patients with different cardiovascular risks that was presented to the focus-group participants.



health centre, the third group comprised older people in good health, the fourth younger people with no major health problems, and the fifth group were patient organization activists, many of whom had chronic conditions. The age range of the interviewees was from 19 to 78 years, and the median age was 51.

#### *Where do you go for health information?*

The Internet, Google and other search engines, were the most important sources of information for those interviewed. Only a few of the oldest participants did not use Google for health information although they might use the Internet in other ways (e.g. paying bills or reading newspapers). Only one participant did not have access to the Internet or did not search for health information online. For people who did not use the Internet, health professionals and relatives were the most important sources of information. Friends, relatives, general and health journals, and books were also consulted. The participants felt that health information was not difficult to find; in fact it was abundant.

Many participants searched for health information before and after they consulted a physician. As concepts of how the patients described the use of health information, we noticed the following: to avoid unnecessary visits to health care and to understand their diagnoses better, to find information on health issues presented in the media, to find help for self-management, for self-medication, and for rehabilitation.

Table II. Demographic characteristics of the 23 participants.

Category	Variable	n	Total
Gender	Female	16	23
	Male	7	
Age	18–29	3	23
	30–39	0	
	40–49	7	
	50–59	2	
	6–69	8	
	> 70	3	
Civil status	Married/cohabitant	13	23
	Single	8	
	Info missing	2	
Occupations			23
	Teacher	2	
	nurse	2	
	technical education	2	
	administrative	6	
	background		
	student	3	
	other	8	23

Sometimes there was too much information, and the participants faced problems with assessing the quality of the information:

If I become dubious of the contents I read in the Internet, I call my daughter or a friend and discuss the topic.

Sometimes it disturbs me that while searching I end up on discussion pages where the information can be mixed.

The variety of health information on the Internet is like a jungle and you can get lost there without the help of friends or other well-informed people.

#### *Concepts on guidelines*

The definition of guidelines was vague to interviewees. In the Finnish language the word for guidelines, “hoitosuosituksset”, means literally “care recommendations”, and many interpreted the term as the recommendations that a physician gives to a patient. Others understood the term as care standards; reference to good quality of care. Only a few of the more informed participants, especially those with experience from patient organizations, knew the exact meaning of the term. More participants were familiar with the Current Care guidelines than the concept of guidelines in general. Current Care guidelines are the large, evidence-based guidelines produced by the Finnish Medical Society Duodecim and are similar to NICE and SIGN guidelines in the UK and Scotland [17].

We observed the concepts of guidelines in the utterances of focus groups and noticed that most often the interviewees saw the guidelines as instructions or standards for health professionals or as information given by a health professional to the patient. Some interviewees also knew that guidelines could be used as material to protect and promote the interests of patients. It was also common that the interviewees did not have a clear concept of guidelines. In Table III we have gathered our classification of concepts and utterances by interviewees that reflect these concepts.

There was little criticism on the contents of guidelines. Expert opinions seemed to be respected and valid to the participants. Two of the best-informed participants knew that with guidelines the limits of care that is publicly funded can be defined, which might have juridical consequences:

I suppose there are good grounds for these recommendations. Why would I not believe the guidelines, if they are so well grounded?

Table III. Concepts of guidelines and quotes from focus-group participants.

Concept	Utterances
1. Instructions for health professionals	<p>"There are guidelines for common diseased, they are general...."</p> <p>"I understand it means [things] such as information on the need for Vitamin D for the population, and that this information is updated from time to time."</p>
2. Standards for health professionals including resourcing	<p>"Is it like a standard, how to proceed with care, this is what I can demand, or what I am allowed to do?"</p> <p>"Sounds like a complex issue, who is the target for guidelines, and must there be public resources for the things that are mentioned in guidelines?"</p>
3. Information given by health professionals to patients	"There seems to be some flexibility around the term. Different medications may have different effects on different people. Maybe the term covers patients also having a word in the treatment decisions?"
5. Material for promotion of interests	<p>"It is a complex issue. In patient organizations there have been questions about this, are guidelines binding in that sense that you must get the treatments that are described in them?"</p> <p>"If there are Current Care guidelines, you can demand the care described in them."</p>
6. No concepts: cannot differentiate guidelines from other health information	"I read articles about health but I am not familiar with this term guidelines."

#### *What kind of information did patients want?*

Very few participants had ever received written information from a physician or nurse but, generally, the focus group participants would have liked it, together with an opportunity to discuss the information with a professional. Some of the most technically competent wished for information in emails rather than on paper, or as a smartphone App. Ideally, they would like a physician to print out the written information and also to individualize it with laboratory results and tailored advice:

In my opinion, the best would be that the physician or nurse advised us on the right information or would give out material. That would create a common pathway in care for us but these have been little utilized so far. As a patient I would like more of such.

One patient had experience of a physician discouraging patients' search for information, and there

was a sense of competition in the amount of information:

My doctor has discouraged me from searching information, he says it's of no use. It has made me think that I knew too much, because he did not like it.

The patients were aware that they did not remember what was said at the consultation, as a woman in her seventies described:

At this age at least, when you are ill and suffering, you cannot remember anything that the physician tells you at the consultation.

#### *Presentation formats*

We presented two of the most frequently used patient versions of bronchitis guidelines in Finland (one produced by Duodecim and one by Tohtori.fi, a commercial source of health information, <http://www.terveyskirjasto.fi> and <http://www.tohtori.fi>, respectively) and asked for participants' comments and criticism. The Duodecim version, with a more structured appearance, subheadings, and shorter paragraphs, was preferred. The commercial version raised suspicions:

Both sites are familiar but the other one seems less trustworthy to me. Somehow I feel that the one with advertisements and discussion pages may not be as reliable. I don't know who produces it but since it's commercial, I trust it less.

Mostly the participants were satisfied with the patient versions. They criticised difficult terms such as "chronic" and "pneumonia", which sound foreign in the Finnish language. They wished for more patient-oriented topics, advice on self-management and when to consult a physician, and less technical language:

Ordinary people do not want research evidence in patient information. Just clear, concise information and instructions for the patient on what to do yourself and when to consult a doctor.

The participants appreciated that the author of the information was presented in the leaflet, and they were more cautious with the other leaflet, which did not present the author. They gave suggestions to improve the presentation by better structuring, links, videos, and stories. The Finnish Medical Society Duodecim was known as an information provider, and it was considered trustworthy, linked to universities and other reliable sources of evidence.

To illustrate cardiovascular risk, we had selected two presentation formats, a drawing or a bar chart (Figures 1 and 2). Generally, the participants preferred the bar chart (i.e. Figure 2); however, this was not a strong preference. They felt the bar charts were more understandable although many felt there was “air”, meaning too much space in this figure. The patients suffering from cardiovascular disease thought the drawing was more frightening and therefore disliked it. However, others liked the idea of the drawing, and they had encountered a similar presentation with small human figures. Both types of presentation were considered useful for health-promotion purposes but not necessarily for patient versions of guidelines.

## Discussion

Although production of guidelines and patient versions has been more active in Finland than in many countries, according to this qualitative study in 2012 our interviewees were not well aware of guidelines. Our interviewees representing patients could not differentiate guidelines from other health information they were exposed to. They felt that health information was abundant and they used Google as their primary source of information. They mainly understood guidelines as instructions or standards for health professionals, as information given by a health professional to the patient, or as material to protect and promote the interests of patients. Often the interviewees did not have a clear concept for guidelines.

The finding that the Internet was the most important source of health information is not surprising, since most Finns use the Internet: 85% of those aged 16 to 89 years were active users of Internet [18]. Although our interviewees were active searchers for health information, they wished for more communication on health information. Patients in our focus groups would have liked to receive more information from their physicians and other health care professionals in print or in electronic formats. They especially wanted an opportunity to discuss the information with a professional but this rarely happened in practice.

Similar findings have been made in other DECIDE consortium studies in the UK (Emma McFarlane, UK National Institute for Health and Care Excellence (NICE), personal communication). Others have reported that the two main functions of the medical consultation include “fostering the relationship” and “information giving” [19]. Patients increasingly bring Internet-based information to consultations, and they hope GPs will have time to discuss, explain, or contextualize it, and to offer a professional opinion [20,21].

Van der Weijden et al. recently studied strategies to facilitate adoption of clinical guidelines for shared decision-making [22]. Their informants suggested several strategies: either patient versions of entire guidelines documents translated into lay terminology or, alternatively, short documents focusing only on specific recommendations and explaining the decision and related diagnostic and treatment options in lay terms. In addition, according to them, patient versions could suggest generic questions that patients can ask their provider. However, these strategies deserve further testing and research on their feasibility and effects in different settings.

Epstein et al. presented five communication tasks for communicating clinical evidence: understanding the patient’s experience and expectations; building a partnership; providing evidence, including a balanced discussion of uncertainties; presenting recommendations informed by clinical judgment and patient preferences; and checking for understanding and agreement [23]. For the individuals we spoke to, it would appear that the presentation formats are less important than other issues in communicating health information well.

The participants in the focus groups were not very critical of the presentation formats of either of the two patient versions based on bronchitis guidelines that we presented to them. They appreciated conciseness and clarity. It seems that guidelines could be better communicated to the public using shorter, clearer messages, which is also the conclusion of the studies by Geiger [24] and Loudon and colleagues [2]. They suggested the guidelines could be made more interesting by better structuring of the information, links to relevant websites, videos, and patient stories. None of the interviewees had recent experience of bronchitis, which may have limited the specific information they could give us, as well as making the theme less interesting to them.

Our interviewees did not have a strong preference for bar charts or drawings when presenting cardiovascular risk. Generally, bar charts were somewhat preferred to drawings, and they were easier to interpret. Patients did not want to be scared by the information they received but did want the opportunity to discuss it with health professionals and seek reassurance. As the participants in our focus groups were relatively unaware of the concept of guidelines, no negative attitudes towards them were expressed. In future, if awareness does increase, patients may raise concerns that guidelines attempt to reduce costs and standardize care at the cost of individual decisions [2].

The strengths of this study were that we interviewed a range of people from those with normal health to those with severe, chronic conditions. The



themes that arose across the focus groups were similar, the data were saturated quickly, and we stopped recruiting after five focus-group sessions. The fact that the participants were largely unaware of the guidelines and the interviewers (HL, OS, and JJ) were people involved in guidelines production may have affected the discussions although low awareness of guidelines among the public has been reported elsewhere [2]. Researchers with a more neutral background perhaps could have led to discussion on additional issues.

A possible weakness of our study is the selection of the interviewees. Since information-rich active patients were searched for, it is likely that on average Finnish patients are not as interested in health information as our interviewees. This also a possible limitation of the focus-group technique, which generally can cause a bias towards the concepts of the more active participants. Probably also the majority of patients are less aware of guidelines than our interviewees.

The fact that the study group had links to guidelines production had several implications. First, instead of creating new theories or concepts around patients' perspectives, we had a more practical aim: to find ideas for producing better patient versions of guidelines. Second, we chose to run the focus groups so that they included methods of user-testing [12,14]: we showed different presentation formats and registered patients' reactions to them. However, despite this practical starting point, our study also created a hypothesis: we conclude that the most urgent point for development and further studies is the lack of communication concerning health information between patients and health professionals.

In conclusion, patients and the public have low awareness of guidelines. Many of them, and not only younger people, are active users of the Internet for health information and they would like more opportunities to discuss the health information with health professionals. Further development is needed to educate health professionals to communicate health information and evidence with patients, and to discuss it during their conversations with patients.

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## Declaration of interest

There are no conflicts of interest in connection with the paper. The authors alone are responsible for the content and writing of the paper.

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